

**Interagency Coordinating Council
Committee Meeting Minutes**

Committee: Health Systems

Recorder: Sheila Wolfe

Date: January 24, 2002

Committee Members

Present: Jean Brunelli, Mary Lu Hickman, Julie Kingsley, Dwight Lee, Mara McGrath, Robin Millar, Peter Michael Miller, Hallie Morrow, Ivette Pena

Staff: Sheila Wolfe

DDS Liaison: Mary Lu Hickman

CDE Liaison: Terence Williams (absent)

Absent: Bonnie Bear, Arleen Downing (chair)

Guests: Diane Kelligrew, Ruth Cook, Linda Landry, Vickie Reis-Allen, Arline Kruger, Toni Gonzales, Nancy Harvey, John Larcabal, Leslie Richard, Maureen Wilson

Summary of Important Points and Actions Considered

- I. **Introductions:** Introductions, including many guests, were made. Mara McGrath and Hallie Morrow chaired the meeting in the absence of Dr. Downing.
- II. **Agenda Review:** The agenda was revised to allow guests, Dr. Leslie Richard and Dr. John Larcabal, to make their special presentations.
- III. **Minutes:** Reviewed and approved from last ICC meeting and interim January 8th meeting.

**IV Presentation Lanterman Regional Center Special Project –
Talking with Parents and Families About their Child’s Disability: Training
for Physicians and other Professions – Presented by Dr. Leslie Richard**

Dr. Richard described the development at Lanterman of the Touch Point Team, composed of three persons who participated in extensive training in Boston with Dr. Berry Brazelton. She noted that this is a widely used and well-respected, relationship-based model for working with families of “typical children” based on providing developmental and anticipatory guidelines. Following the training, the Lanterman team adapted the model and added new materials for working with families of children with developmental difficulties and atypical development.

The new Lanterman model provides a 3-day “training of trainers” curriculum which includes a new video focused on how to talk with people when there is “bad news” and difficult information to convey. This new video is introduced by Dr. Brazelton and focuses on creating empathetic relationships. Dr. Richard presented and explained the video which received very positive responses from the committee and guests.

Future training plans include use of the video and other materials, for training for the Lanterman Regional Center staff, medical students and residents. Other modules in the series include, dealing with grief, valuing the issues and passion that families of children with special needs may have and developing collaborative partnerships.

Dr. Richard and her partner, Maureen Wilson, recommended that other regional centers consider training in the Touch Points model and use of the adaptation. Other Touch Point resources in California include the teams in Napa, Sonoma and San Mateo counties and it was suggested that on-line and distance learning options be considered in the future.

For more information and/or follow-up training contact: Maureen Wilson, Director of Training and Development - Lanterman Regional Center. 213/383-1300 ext. 719 or email – maureen.wilson@lanterman.org

IV. Operation Bright Start and Kids Welcome Here – Special Projects of the American Optometric Association – Overview by John Larcabal, O.D. of Norwalk, Ca.

Dr. Larcabal, a special guest, briefly described his interest and the interest of the Association in early vision screening and follow-up services. He noted that the field recognizes the difficulties in performing vision screenings and more in-depth assessments with very young children and young children with disabilities. As a result, a new Children’s Vision Task Force has been formed in the California Optometry Association. The committee members and guests were encouraged to contact the association for more information and to contact Dr. Larcabal directly at 562/868-8233 or email jlarcabal@aol.com for more information and/or follow-up services.

V. Follow-Up and Recommendations for Vision and Hearing Screening

Dr. Downing’s notes and recommendations from the interim meeting were presented and Dr. Miller led a discussion and follow-up planning.

General recommendations included the need for;

- a. a uniform form for screening, assessment and reporting

- b. a cover letter regarding Early Start, the timelines, the provisions of the IFSP and the Physician/Health Care Provider Brochure to accompany the form requesting vision and/or hearing screening/assessments
- c. collecting and reviewing the forms that regional centers are already using successfully and the ones used by CCS
- d. clear information of what is needed and most appropriate for screening and assessing vision and hearing with children from birth to three – including possible implications of a disability on vision and/or hearing
- e. more support in rural communities to access trained professionals
- f. on-going contact with primary care physicians and specialists in the field to determine current practices and needs
- g. a “triage model” to screening/assessment
- h. increased coordination with the California Dept. of Health – Children’s Medical Services/California Children’s Services (CMS/CCS) regarding work with physicians involved in Medical Treatment Units (MTU’s)
- i. clear information on what is a complete evaluation for vision and hearing
- j. increased recognition that children with CCS eligible conditions are in need of uniform exams related to vision and hearing and CCS forms be reviewed and/or adapted for such exams
- k. increased recognition that children eligible for Early Start may often be at high risk for related or associated vision and/or hearing problems
- l. all children, birth to three, to receive basic screens in vision and hearing and resources for follow-up if problems are suspected (coordinate with other community agencies)
- m. both initial and on-going screenings and assessments in vision and hearing as an integral part of IFSP development and revision – recognizing that early difficulties may go undetected and/or may emerge throughout the early years
- n. a team approach, more communication and coordination with the child’s primary health care provider and strategies for clear communication of the results to be included within the recommendations

Plan and Next Steps

- Dr. Miller to coordinate with Dr. Downing and others on a review and refinement of the “almost final” version of the recommendations in this area – Dr. Miller to do initial work and send copies to Dr.’s Downing, Hickman, Morrow and Pena for input/review prior to March meeting
- Review revised document at March Meeting – committee members to receive document after review prior to the meeting – by email and/or hard copy (HSC staff to assist as needed by Dr.s Miller and Downing)
- Plan for Action Item at May meeting

VI. CHDP Overview – Hallie Morrow (see attached materials)

An overview of the proposed Governor’s budget was presented and concerns regarding cutbacks in the CHDP program were discussed. DHS is convening a stakeholders group on 2/1/02. in Sacramento to discuss options for change. Committee members and guests were encouraged to connect with local CHDP programs and providers for more information and/or to contact DHS through email – ayukl@dhs.ca.gov or at 916/327-0360

VII. Newborn Hearing Screenings – Hospital Certification

Thirty-six hospitals are currently on board and several are in line or pending. To be certified, a hospital must offer screening to all CCS approved children served in the NICU’s and offer funding through Medi-Cal and for the uninsured. Some private hospitals may or may not be providers.

VIII. New Genetics Disease Branch – Expanding Screening – policy attached

IX. CMS Asthma Assessment Guidelines – New guidelines being re-issued through State Prop 10 Initiative. (see attached)

X. DDS Update – Dr. Hickman

An update was presented on the two major autism research studies now underway:

The Center on Environmental Factors in the Etiology of Autism – a 5-year grant from the National Institute for Environmental Health Science to the University of California, Davis; and

The California Center of Excellence for Autism Epidemiology – a 5-year grant from the Federal Centers for Disease Control and Prevention (CDC) to the Department of Health Services.

Both of these centers will cooperate extensively to collect data and will involve regional centers and schools in reaching families who may wish to participate in studies:

DDS will also be involved with the Mind Institute in planning outreach and screening for Fragile X; and with Stanford in seeking a twin study for families with autism.

DDS and CEI-TAN are also working on revisions and additions to the Early Start Service Coordinator's Handbook. There will be an updated section on Health Status and related responsibilities of the service coordinator and IFSP teams.

Proposed Agenda Items for March Meeting

1. Review of Vision Screening/Assessment Recommendations paper – prepare for submission as an Action Item for full ICC in May
2. Follow-up on next steps and recommendations for use of video and related materials on autism from New Jersey “First Signs” group
3. Discuss new priorities for the HSC and future plans
4. Overview of the Family Voices Initiative – Juno Duenas